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DOI:

[10.1016/j.jss.2016.02.011](https://doi.org/10.1016/j.jss.2016.02.011)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Kelly, K. N., Noyes, K., Dolan, J., Fleming, F., Monson, J. RT., Gonzalez, M., Sevdalis, N., & Dozier, A. (2016). Patient Perspective on Care Transitions after Colorectal Surgery. *Journal of Surgical Research*.
<https://doi.org/10.1016/j.jss.2016.02.011>

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Accepted Manuscript

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PII: S0022-4804(16)00075-5

DOI: [10.1016/j.jss.2016.02.011](https://doi.org/10.1016/j.jss.2016.02.011)

Reference: YJSRE 13666

To appear in: *Journal of Surgical Research*

Received Date: 6 November 2015

Revised Date: 18 January 2016

Accepted Date: 11 February 2016

Please cite this article as: Kelly KN, Noyes K, Dolan J, Fleming F, Monson JR, Gonzalez M, Sevdalis N, Dozier A, Patient Perspective on Care Transitions after Colorectal Surgery, *Journal of Surgical Research* (2016), doi: 10.1016/j.jss.2016.02.011.

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Patient Perspective on Care Transitions after Colorectal Surgery

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Acknowledgement and Disclosures: The study was in part supported by an ASCRS resident research grant (KK) and a program grant from the Wilmot Cancer Institute (KN, JRTM). Dr. Sevdalis' research was supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South London at King's College Hospital NHS Foundation Trust. NS is a member of King's Improvement Science, which is part of the NIHR CLAHRC South London and comprises a specialist team of improvement scientists and senior researchers based at King's College London. Its work is funded by King's Health Partners (Guy's and St Thomas' NHS Foundation Trust, King's College Hospital NHS Foundation Trust, King's College London and South London and Maudsley NHS Foundation Trust), Guy's and St Thomas' Charity, the Maudsley Charity and the Health Foundation. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. Dr. Sevdalis is the Director of London Safety & Training Solutions Ltd, which provides team skills training and advice on a consultancy basis in hospitals and training programs in the UK and internationally.

Category for the paper: Gastrointestinal

Abstract:

Background: The surgical care pathway is characterized by multiple transitions, from pre-operative assessment to in-patient stay, discharge from hospital and follow-up care. Breakdowns in one phase can affect subsequent phases, which in turn can cause delays, cancellations, and complications. Efforts to improve care transitions focused primarily on post-discharge care coordination and inpatient education for medically complex patients have not demonstrated consistent effects. This study aimed to understand the expectations and perceptions of postoperative inpatients regarding transition from hospital to home in an effort to reduce patient burden.

Materials and Methods: Patients who underwent a colorectal resection at a large academic medical center and were discharged home were eligible to participate in the study. Patients were recruited during their postoperative hospital stays and interviewed over the phone within a week after discharge about their perceptions of care, values, and attitudes. Overall, we recruited 16 patients with benign (n=8) and malignant (n=8) indications. Recruitment continued until theme saturation.

Results: Factors that shaped patients' understanding of post-surgical recovery and that motivated them to seek provider attention post-discharge fell into three major groups: patient expectations vs. reality, availability and role of informal caregivers in the postoperative recovery process, and communication as a key to patient confidence and trust.

Conclusions: For patients and caregivers, postoperative planning starts long before surgery and hospital admission. Providers should consider these dynamics in designing interventions to improve care transitions, patient satisfaction and long-term outcomes. This study was limited to colorectal surgical patients treated in a single institution and may be not generalizable to other surgical procedures, non-academic settings or different regions.

Key Words: colorectal, hospital discharge, qualitative research, patient perspective, informal caregiver, communication

1. Introduction

The number of surgical procedures performed annually in the United States continues to grow and now exceeds 14 million[1]. The surgical care pathway is characterized by multiple transitions, from pre-operative assessment to in-patient stay, discharge from hospital and follow-up care. Providing optimal care across the all phases of the surgical pathway has become increasingly challenging, due to the complexity of procedures, increasing time pressures on staff, and demands for a patient-centered approach[2]. The planning and execution of postsurgical discharges for cancer patients is of particular interest, since post-discharge complications may lead to hospital readmissions, delays in adjuvant treatment, poor cancer outcomes[3-7] and provider penalties[8-12]. Hospital discharge for frail older patients is further complicated because of the increased need to coordinate rehabilitation, home care services, and transportation and to be inclusive of informal care-givers.

Surgical admissions are different from most medical admissions in that a large proportion of surgical procedures are elective rather than emergent. Despite the opportunity to plan and prepare prior to surgery, efforts to reduce complications and minimize readmissions have largely focused on post-discharge care coordination plus some in-hospital training and education opportunities for high risk patients, with mixed results[13, 14]. The most effective interventions are complex multidisciplinary programs that emphasize the patient's ability for self-care and communication among all members of the care team[13, 14]. Previous studies have demonstrated, however, that surgical patients often have unrealistic or inaccurate expectations about the effects of their operations and their post-surgical function and recovery process[15]. This misalignment may negatively affect patients' ability to prepare for and cope with the post-

surgical recovery process[15-19]. Finally, the time in the hospital immediately following a surgical procedure is not optimal for learning new self-care skills[5, 20].

Qualitative research methods are particularly suited to gaining a deeper understanding of the patient perspective on factors affecting care transitions and to identifying appropriate metrics and outcomes for subsequent quantitative studies. In-depth interviews, although not intended to generate statistically representative results, are the main approach to examine how patients form expectations about surgery and recovery, and how they cope with stress, uncertainty and complications. The aim of this qualitative study was to examine patient perspectives on their post-surgical experience, something that has not been well understood in the past. Ultimately, our goal is to identify modifiable factors and strategies as targets for quality improvement and to redesign the processes of care to improve patients' experiences after major abdominal surgery.

2. Materials and Methods

To develop the study protocol and to guide the analysis, we followed the commonly used qualitative study checklist and the Consolidated Criteria for Reporting Qualitative Research developed by Tong et al [21]. We developed an interview guide (Appendix, Table 1A) with the following domains of investigation informed by prior studies[3-9, 13, 14, 16-20, 22-30] : (1) readiness for hospital discharge; (2) physical functioning; (3) emotional functioning; (4) social functioning; (5) informal caregivers. We also included open-ended questions regarding patient perceptions on each of these general domains as well as on their disease and recovery and their relative importance.

2.1 Sampling framework

Using stratified purposive sampling, we recruited patients age 18 years or older, undergoing colon or rectal resection (either benign or malignant indication) at a large academic medical center according to standardized care protocols between December 2013 and March 2014 (Table 1) [23] [24, 25]. The recruitment strategy aimed to identify a diverse group of patients in order to include a wide variety of patient experiences. The patients' advanced practice providers (APP) introduced the study to the patients in the hospital setting, and written informed consent was obtained prior to discharge. Institutional Review Board approval for the study was obtained prior to subject recruitment and any data collection (RSRB Approval 000049044). Subjects who lacked capacity to consent and those who needed a stay in a skilled nursing facility were excluded. With the rolling study design, recruitment and patient interviews continued until theme saturation was reached. "Saturation" is an approach used for purposive samples, the most commonly used form of nonprobabilistic sampling for qualitative studies. This approach relies on the concept of "saturation," the point at which no new information or themes are observed in

the data as more subjects are recruited and interviewed. In our study, theme saturation was determined by the study team through an ongoing preliminary analysis of recorded patient interviews.

Once a patient agreed to participate in the study, the study coordinator abstracted socio-demographic (age, sex, race, availability of a caregiver), clinical (preoperative diagnosis and comorbidities, functional status) and hospital data (type of procedure, attending surgeon, and presence or absence of a stoma[31-36]) from the electronic medical record.

2.2 *Semi-structured interviews*

Patients were interviewed over the phone 3-5 days after discharge. Semi-structured interviews were used to gather data concerning patients' experiences with the discharge process and the transition to home including perceptions about information and support provided to them in the discharge planning process (Appendix, Table 1A). Each interview, 10-30 minutes long, was audiotaped and transcribed verbatim by online software. The analysis described below occurred in an ongoing manner as patients were recruited and interviews conducted. This strategy allowed preliminary study findings to inform subsequent interviews, helped explore new or unanticipated areas, prompted recruitment of specific patient subgroups and allowed ascertainment of saturation of the themes.

2.3. *Analysis Plan*

2.3.1. Analysis Overview

To ensure consistency in data interpretation, one member of the study team performed the initial code extraction and analyzed all interviews using thematic content analysis [37]. Content

analysis is a widely used qualitative research technique designed to interpret meaning from the content of text data. The technique relies on extraction of qualitative ‘themes’ from the textual data. These are derived by the researcher(s) doing the theme extraction, and reviewed for meaningfulness and consistency. The general flow of the overall analysis was as follows: 1) Review of individual interviews; 2) Identification of possible broad codes (noted on the transcripts) using the relevant codes reported by other investigators [15-19]; these were finalized once the majority of interviews was completed; 3) Secondary analysis of all interviews applying the final set of codes, and identification of relevant patient quotes that exemplified these codes; 4) Subgroup analysis (i.e. male/female, readmitted/not readmitted, stoma/no stoma, etc.). 5) Re-grouping of the codes into broader themes and domains; 6) Comparison of the domains across patient subgroups (Table 2). This process was designed to construct theories that are grounded in the data themselves[39].

2.3.2. *Analysis Validation*

We took care to quality-assure the data analysis procedure. To minimize any investigator bias and to validate the interpretation of the analysis, a random subset of interviews was also analyzed by different investigators within our team, who were not involved in the patient interviews – and hence their thematic extraction could not possibly be affected by views formed during the interviews. This procedure allowed us to systematically check and corroborate independently derived thematic codes as derived by our dataset. Throughout the analytical procedure, all disagreements were discussed at joint meetings between the study team, clinical personnel involved in surgical care, and patient stakeholders. Additional information obtained from patient medical records and from care providers was used for confirmation and analysis

triangulation (e.g., when a patient reports that nobody told him about the possibility of functional limitations after the surgery, but the consent letter signed by the patient and attached to his electronic medical record described possible limitations and how to manage them at home).

3. Results

3.1. *Characteristics of the Study Sample*

The final patient sample consisted of 16 patients who underwent colorectal resections between November 2013 and March 2014. All patients (n=17) approached for consent agreed to participate; one patient, however, was unavailable for contact and was excluded from the analysis. Patients ranged in age from 29-94 years (mean: 58.1 years, median: 59.5 years) (Table 3).

Five attending surgeons performed the operations, and each surgeon performed between 2 and 6 cases on study subjects. All 16 cases started laparoscopically or robotically; 2 cases (12.5%) converted to open procedures. Six patients (37.5%) had a stoma created during surgery (5 ileostomies, 1 colostomy). Postoperative length of stay ranged from 3-22 days (mean: 7 days, median: 4 days). Nine patients (56.3%) were discharged home with visiting nursing services. One patient was readmitted and another patient presented to the emergency room within 30 days of surgery.

All 16 patients had an informal caregiver helping them with some aspect of care or day-to-day activities at home. All eight men had a spouse or significant other as their primary informal caregiver. Three women had a spouse or significant other, 3 women had their daughters and 2 women had their mothers as primary informal caregivers.

3.2. *Patient Interviews*

The interviews yielded 144 pages of transcribed text for analysis. We identified three major themes regarding the transition from hospital to home following colorectal surgery: 1) patient expectations versus reality, 2) role of informal caregivers in the recovery process, and 3)

role of patient-provider communication in building confidence and trust. These themes are described in detail below. Content analysis of the patient interviews did not reveal any consistent differences on the basis of age or socio-economic status. Therefore, we applied a single coding structure to the entire data set.

3.2.1. Theme 1: Patient Expectations versus Reality

Patients discussed their preoperative expectations including how the expectations were formed and how they evolved during the experience (Table 4). Additionally, patients reported whether their expectations were consistent with their actual experiences during the postoperative period. Selected quotes for this theme are displayed in Table 4 grouped by corresponding domains: expectations formed based on communications with providers or other patients, accurate and inaccurate expectations based on patients' own experiences, "new baseline" after surgery, and experiences of patients without any prior knowledge.

Patients commonly established a context for the operation by comparing it to a previous medical experience, hospitalization, or surgery. Within this theme, we observed consistent variation in responses based upon the respondent's sex and whether the patient had a stoma. Women referenced a previous surgical experience with a hysterectomy or C-section, while men described a wider variety of experiences with non-surgical treatment. For instance, a laparoscopic appendectomy performed several years prior did not help a patient form realistic expectations about open colectomy with ileostomy, while a previous cesarean section provided women with an accurate anchor for what to expect during recovery after laparotomy (e.g., ability to walk up and down the stairs, shower, perform light house work). Patients with a stoma prior to surgery compared their new stoma to the previous stoma, which helped many of them form

realistic expectations of the recovery process and plan for assistance or efficient self-care.

Additionally, patients' views of their post-surgical experiences were colored by the reasons they chose to have the surgery in the first place. For instance, if a patient reported that his decision to have surgery was driven by pain and discomfort associated with cancer, then postoperative pain represented less of an issue for this patient; this patient was more satisfied and less anxious and generally reported fewer problems during the recovery period.

3.2.2. Theme 2: Caregivers' Role and Assistance in the Postoperative Recovery Process

Informal caregivers, including children, spouses and parents, played many important roles, assuming some of the activities that might have been part of the patient's previous routine as well as taking on new responsibilities related to the recent hospitalization. Patients discussed the important roles their informal caregivers played in their daily lives, including grocery shopping, cooking, cleaning, as well as helping with new medical needs such as wound and stoma care (Table 5).

Caregivers' abilities to fulfill those roles, however, were not always sufficient, and additional task-specific training might have been warranted. Hospital-provided education and training for patients and their informal caregivers included topics and skills such as wound care, drain and stoma management, and injection of low molecular weight heparin for venous thromboembolism prophylaxis. Patients expressed irritation, however, that the timing of their in-hospital training did not take into account care-givers' availability, making it difficult for the informal caregivers to be present while the training occurred (Table 5).

Finally, patients reported feeling guilty and uncomfortable because, although they needed their caregivers to assist them, they did not want to become a burden. They reported their

caregivers had to take on extra responsibilities or go out of their way to visit and were concerned with the effect this had on the caregivers (Table 5). All patients reported that this help was critical, but they were eager to become self-sufficient as soon as possible.

3.2.3. Theme 3: Communication as a Key to Patient Confidence and Trust

Patients reported that good communication helped foster confidence and trust in the system or in their providers (Table 6). Patients reported feeling “comfortable” at the hospital, appreciated when providers took time to thoroughly explain a procedure or their condition, and liked the “team approach” to inpatient care. Even when the postoperative course was complicated, patients retained this confidence in their providers and the system, as long as lines of communication remained open. The few instances of failed trust or confidence were generally related to miscommunication. For instance, patients reported feeling anxious and confused when they received different messages about their treatment or discharge plan from nursing on different shifts or from different members of their care team (e.g., residents vs. attending vs. nurse coordinator). On the other hand, when the message was consistent (e.g., regarding training or discharge date), patient confidence usually improved (Table 6).

Respondents appreciated clear and consistent messages regarding their care from their providers preoperatively, during their hospital stays, and postoperatively at home. Consistency among providers, nurses, and other staff members was perceived as a “team approach”. Patients noted that various nurses in the hospital or at home performed certain care tasks (e.g., stoma care, wound or drain management) differently and that these differences were confusing, especially while they were still trying to learn how to do the tasks for themselves.

All patients reported receiving sufficient information at discharge and knew whom to contact if they had problems. Several patients received their surgeons' direct phone numbers, although none felt a need to use this resource. Having a clear understanding of whom to contact if problems arose and knowing that help was available if needed made patients feel more comfortable during the post-discharge recovery process (Table 6).

4. Discussion

This study examined the expectations and perceptions of surgical inpatients during the post-discharge period in order to understand the patient recovery process following major surgery and to identify targets for quality improvement. Our findings suggest that the information that patients and their informal caregivers receive during the entire patient journey plays a major role in post-discharge recovery. Three major themes emerged regarding the factors that shape patient understanding of postoperative recovery and that motivate them to contact their provider or clinic or seek medical care: patient expectations versus reality, the role of informal caregivers in the postoperative recovery process, and communication as a key element of patient confidence and trust.

We observed that patients often, when discussing their postoperative progress, put their surgical experience into the context of their previous medical history. This tactic was more common among men than among women and among patients with substantial prior healthcare experiences than among patients who did not have significant experiences to draw from. If a patient had a prior hospitalization, operation, or healthcare experience, then this event (“the anchor”) generally formed the basis of his/her expectations about the current recovery process. Naturally, the choice of the anchor had a significant impact on patient perceptions. An inappropriately chosen anchor could have a greater negative impact on patients' surgical experiences and expectations for recovery than no anchor at all. Explaining the surgical procedures under consideration and expectations for the recovery process within the context of a patient's past experiences may help better prepare patients and their caregivers for a major abdominal operation and minimize complications and unexpected problems.

Many patient expectations started to unfold and deviate from reality during the early postoperative and post-discharge period. One common finding in our study was that while patients welcomed the education and training they received from providers before their procedures, this information was not sufficient or appropriate enough for them to develop accurate expectations. We argue that lack of accurate expectations makes self-caring harder and complicates the work of the informal care-givers. For instance, if the patient expected that she would be able prepare her own meals when she came home from the hospital, but then realizes that she is too fatigued to cook, she may become malnourished and dehydrated and require even more help from her daughter who comes to check on her every other day. Furthermore, many patients admitted that despite the training they received for wound and stoma care, they still depended significantly on the help and assistance of their informal caregivers who generally were not present for the special skills training in the hospital. This finding was consistent with previous published reports indicating that patients retain very little of what is conveyed before or during discharge[40] and that only 20% of caregivers received information regarding what complications to look for at home[5]. This evidence demonstrates the importance of considering informal caregivers as a critical part of the patient care team and incorporating them, as much as possible, into all pre-, peri- and post-surgical patient education, training and communication activities[41, 42]. Additional research is needed to better understand the optimal time window for discharge planning and the best strategies for forming realistic patient expectations about the post-discharge recovery process [15].

Many patients in our study emphasized that consistency of communication across time (preoperative-postoperative) and among all providers involved in their care (e.g., medical and surgical teams, APPs and clinical trainees) was very important to their perception of the overall

hospital experience and that inconsistent information received from their care teams was one of the primary frustrations in the study. Similar findings have been reported in medical and surgical patient populations across different healthcare systems[20, 43-45], emphasizing that good communication is one of the major factors affecting patient-doctor relationships and helps patients form trust in their health care providers. Not surprisingly, successful readmission reduction interventions have included a nursing care manager [46-49] or coach[50, 51] and have focused on communication between the patient and the rest of the care team.

This study has some inherent limitations. It was performed on a convenience sample of patients undergoing surgery at a single institution. Although insurance status, age and a number of clinical factors were reasonably widely represented in our sample, we did not achieve racial diversity in the investigated patients – this may have affected the overall thematic findings. Further, while these data were extremely rich and detailed, our findings may not be generalizable to other surgical specialties, institutions, or community health systems. Additionally, the data presented here were collected during the early post-discharge period, and further research should examine later time periods, including unplanned ED visits and hospital readmissions. Further work should also incorporate the views and perceptions of providers and informal caregivers who may view the care process differently from the patients.

In summary, while much of the recent literature on improving the quality of inpatient surgical care has focused on finding clinical factors to identify patients at risk for post-discharge complications, our results suggest that the risk of adverse events and poor recovery are also affected by other factors and events that have taken place earlier in the patient journey and may not be directly related to surgical care. These factors include prior medical history and experiences with the healthcare system, availability and skills of informal caregivers, provider

communication, and other institutional processes and practices (e.g., surgical consent process, scheduling of patient training).

This study is a part of our larger research program focused on improving quality of care in surgical oncology. The qualitative analysis reported here was the first stage in our investigation aiming to examine quality of care paradigm from patient perspective and identify new, previously unaddressed targets for practice improvement. Questionnaires like Consumer Assessment of Healthcare Providers and Systems (CAHPS) use closed questions that have one correct answer or that give limited options to the respondents to answer. Open ended questions, like the questions we used for patient interviews, do not have a perfect/correct answer and hence, require a person to come up with additional details and information. Semi-structured patient interview approach is better suited for the goal of our study to explore patient's views, attitudes, knowledge and beliefs about post-surgical discharge and to identify novel domains, mechanisms and factors that researchers have not yet incorporated into standardized tools (like CAHPS or SF-36).

Based on the results of our qualitative investigation report here, we are developing subsequent quantitative studies to redesign the processes of care after major abdominal surgery, to implement the new care pathway and to conduct a quantitative comparative effectiveness evaluation of the new pathway compared to the current standard. Our findings also emphasize the importance of teamwork and communication among all members of patient care team, better links between patient prior experience interacting with healthcare system and care planning, and the need to more systematically include patient caregivers in decisions about post-discharge care. More research is needed to identify effective and sustainable strategies to address patients' individual needs and their information gaps and misconceptions about post-operative care and

the recovery process and to better understand the role of informal caregivers in surgical recovery process.

References:

1. Semel, M.E., et al., *Rates and patterns of death after surgery in the United States, 1996 and 2006*. Surgery, 2012. **151**(2): p. 171-182.
2. Nehme, J., et al., *The Use of Multimedia Consent Programs for Surgical Procedures A Systematic Review*. Surgical innovation, 2013. **20**(1): p. 13-23.
3. Bours, G.J., et al., *The effects of aftercare on chronic patients and frail elderly patients when discharged from hospital: a systematic review*. Journal of advanced nursing, 1998. **27**(5): p. 1076-1086.
4. Cummings, S.M., *Adequacy of discharge plans and rehospitalization among hospitalized dementia patients*. Health & social work, 1999. **24**(4): p. 249-259.
5. Driscoll, A., *Managing post-discharge care at home: an analysis of patients' and their carers' perceptions of information received during their stay in hospital*. Journal of Advanced Nursing, 2000. **31**(5): p. 1165-1173.
6. Tilus, S.L., *The influence of nursing education on collaborative discharge planning*. Journal for Nurses in Professional Development, 2002. **18**(5): p. 274-281.
7. Naylor, M.D., et al., *Cognitively Impaired Older Adults: From Hospital To Home: An exploratory study of these patients and their caregivers*. AJN The American Journal of Nursing, 2005. **105**(2): p. 52-61.
8. Williams, M.V., *A requirement to reduce readmissions: take care of the patient, not just the disease*. Jama, 2013. **309**(4): p. 394-396.
9. Fontanarosa, P.B. and R.A. McNutt, *Revisiting hospital readmissions*. JAMA, 2013. **309**(4): p. 398-400.
10. Cms.gov. *Hospital Value-Based Purchasing 2014* December 18th 2014; Available from: <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/hospital-value-based-purchasing/index.html?redirect=/hospital-value-based-purchasingref>.
11. Cms.gov. *Bundled Payments for Care Improvement (BPCI) Initiative*. 2015 August 20th 2015 [cited May 10th 2015]; Available from: <http://innovation.cms.gov/initiatives/bundled-payments/>.
12. health.ny.gov. *Delivery System Reform Incentive Payment (DSRIP) Program*. 2015 September 1 2015; Available from: https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/.
13. Leppin, A.L., et al., *Preventing 30-day hospital readmissions: a systematic review and meta-analysis of randomized trials*. JAMA internal medicine, 2014. **174**(7): p. 1095-1107.
14. Dhalla, I.A., et al., *Effect of a postdischarge virtual ward on readmission or death for high-risk patients: a randomized clinical trial*. JAMA, 2014. **312**(13): p. 1305-1312.
15. Park, J., et al., *Patient Expectations of Functional Outcomes After Rectal Cancer Surgery: A Qualitative Study*. Diseases of the Colon & Rectum, 2014. **57**(2): p. 151-157.
16. Neuman, H.B., et al., *Rectal cancer patients' quality of life with a temporary stoma: shifting perspectives*. Diseases of the Colon & Rectum, 2012. **55**(11): p. 1117-1124.
17. Thompson, A.G. and R. Sunol, *Expectations as determinants of patient satisfaction: concepts, theory and evidence*. International Journal for Quality in Health Care, 1995. **7**(2): p. 127-141.
18. Koller, M., et al., *Expectations and quality of life of cancer patients undergoing radiotherapy*. Journal of the royal society of medicine, 2000. **93**(12): p. 621-628.
19. Phillips, P.S., et al., *Rectal cancer in the elderly: patients' perception of bowel control after restorative surgery*. Diseases of the colon & rectum, 2004. **47**(3): p. 287-290.
20. Connolly, M., et al., *Systems and people under pressure: the discharge process in an acute hospital*. Journal of clinical nursing, 2009. **18**(4): p. 549-558.

21. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups*. International Journal for Quality in Health Care, 2007. **19**(6): p. 349-357.
22. Park, J., et al., *Patients' expectations of functional outcomes following rectal cancer surgery: a qualitative study*. Diseases of the colon and rectum, 2014. **57**(2): p. 151.
23. Simunovic, M., et al., *Influence of delays to nonemergent colon cancer surgery on operative mortality, disease-specific survival and overall survival*. Canadian Journal of Surgery, 2009. **52**(4): p. E79.
24. Varadhan, K.K., et al., *The enhanced recovery after surgery (ERAS) pathway for patients undergoing major elective open colorectal surgery: a meta-analysis of randomized controlled trials*. Clinical nutrition, 2010. **29**(4): p. 434-440.
25. Arriaga, A.F., et al., *The better colectomy project: association of evidence-based best-practice adherence rates to outcomes in colorectal surgery*. Annals of surgery, 2009. **250**(4): p. 507-513.
26. Kelly, K.N., et al., *Risk factors associated with 30-day postoperative readmissions in major gastrointestinal resections*. Journal of Gastrointestinal Surgery, 2014. **18**(1): p. 35-44.
27. Kassin, M.T., et al., *Risk factors for 30-day hospital readmission among general surgery patients*. Journal of the American College of Surgeons, 2012. **215**(3): p. 322-330.
28. Kariv, Y., et al., *Multivariable analysis of factors associated with hospital readmission after intestinal surgery*. The American journal of surgery, 2006. **191**(3): p. 364-371.
29. Messaris, E., et al., *Dehydration is the most common indication for readmission after diverting ileostomy creation*. Diseases of the Colon & Rectum, 2012. **55**(2): p. 175-180.
30. González, J.R., et al., *Sex differences in hospital readmission among colorectal cancer patients*. Journal of epidemiology and community health, 2005. **59**(6): p. 506-511.
31. Kelly, K.N., et al., *Risk Factors Associated with 30-Day Postoperative Readmissions in Major Gastrointestinal Resections*. J Gastrointest Surg, 2013.
32. Kassin, M.T., et al., *Risk factors for 30-day hospital readmission among general surgery patients*. J Am Coll Surg, 2012. **215**(3): p. 322-30.
33. Kariv, Y., et al., *Multivariable analysis of factors associated with hospital readmission after intestinal surgery*. Am J Surg, 2006. **191**(3): p. 364-71.
34. Messaris, E., et al., *Dehydration is the most common indication for readmission after diverting ileostomy creation*. Dis Colon Rectum, 2012. **55**(2): p. 175-80.
35. Robinson, T.N., et al., *Frailty predicts increased hospital and six-month healthcare cost following colorectal surgery in older adults*. Am J Surg, 2011. **202**(5): p. 511-4.
36. Gonzalez, J.R., et al., *Sex differences in hospital readmission among colorectal cancer patients*. J Epidemiol Community Health, 2005. **59**(6): p. 506-11.
37. Vaismoradi, M., H. Turunen, and T. Bondas, *Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study*. Nursing & health sciences, 2013. **15**(3): p. 398-405.
38. Fereday, J. and E. Muir-Cochrane, *Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development*. International journal of qualitative methods, 2008. **5**(1): p. 80-92.
39. Charmaz, K., *Constructing grounded theory: A practical guide through qualitative analysis (Introducing Qualitative Methods Series)*. 2006.
40. Makaryus, A.N. and E.A. Friedman. *Patients' understanding of their treatment plans and diagnosis at discharge*. in *Mayo Clinic Proceedings*. 2005. Elsevier.
41. Coleman, E.A., et al., *Enhancing the Care Transitions Intervention Protocol to Better Address the Needs of Family Caregivers*. Journal for Healthcare Quality, 2015. **37**(1): p. 2-11.

42. Coleman, E.A. and S.P. Roman, *Family Caregivers' Experiences During Transitions Out of Hospital*. Journal for Healthcare Quality, 2015. **37**(1): p. 12-21.
43. McMurray, A., et al., *General surgical patients' perspectives of the adequacy and appropriateness of discharge planning to facilitate health decision-making at home*. Journal of clinical nursing, 2007. **16**(9): p. 1602-1609.
44. Holland, D.E., P. Mistiaen, and K.H. Bowles, *Problems and unmet needs of patients discharged "home to self-care"*. Professional case management, 2011. **16**(5): p. 240-250.
45. Regenbogen, S.E., et al., *The effect of complications on the patient-surgeon relationship after colorectal cancer surgery*. Surgery, 2014. **155**(5): p. 841-850.
46. Naylor, M.D., et al., *Comprehensive discharge planning and home follow-up of hospitalized elders: a randomized clinical trial*. Jama, 1999. **281**(7): p. 613-620.
47. Naylor, M.D., *Comprehensive discharge planning for hospitalized elderly: a pilot study*. Nursing Research, 1990. **39**(3): p. 156-160.
48. Naylor, M.D. and D. Brooten, *The roles and functions of clinical nurse specialists*. Image: the Journal of Nursing Scholarship, 1993. **25**(1): p. 73-78.
49. Naylor, M.D., et al., *Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial*. Journal of the American Geriatrics Society, 2004. **52**(5): p. 675-684.
50. Coleman, E.A., et al., *The care transitions intervention: results of a randomized controlled trial*. Archives of internal medicine, 2006. **166**(17): p. 1822-1828.
51. Parry, C., et al., *Further application of the care transitions intervention: results of a randomized controlled trial conducted in a fee-for-service setting*. Home health care services quarterly, 2009. **28**(2-3): p. 84-99.

APPENDIX**Table a1: Patient Interview Guide**

Tell me about your experience being discharged from the hospital.

Probes:

What's happened since you got home from the hospital?

What information did you receive about your discharge and recovery at home?

Sub-probes: content, sufficient, who gave information to you, how

Was there anything you were worried about that happened (or didn't happen) at home?

Sub-probes: "bumps in the road", prepared for this, what resources were available

Tell me about the help you had at home after surgery?

Patients were offered a \$20 gift card after completing the interview.

Table 1: Sampling framework groups

<i>Primary Criteria</i>	
Male	Female
Age ≤ 65 years	Age > 65 years
Stoma	No stoma
<i>Potential Secondary Criteria</i>	
Open surgery	Laparoscopic surgery
Malignant pathology	Benign pathology
Caregiver at home	No caregiver at home
Postoperative complication	No postoperative complications
Short length of stay	Prolonged length of stay
Unplanned 30-day readmission	No 30-day readmission

Table 2: Example of a coding matrix

	Quote	Male	Female	<65 years	≥65 years	Ostomy	No Ostomy
Caregiver at Home							
Patient 1	"I depended on my wife to help with things around the house."	X			X		X
Patient 2	"My spouse took detailed notes"	X		X			X
Patient 9	"It was hard to manage by myself"		X		X		X
Acquisition of Skills							
Patient 3	"They made sure I could change my ostomy bag by myself"		X	X		X	
Patient 2	"The incisions healed fast, there wasn't much for me to do."	X		X			X
Patient 6	"I was really nervous about changing my own dressings"		X		X	X	
Timing of Discharge							
Patient 6	"They kicked me out too fast"		X		X	X	
Patient 4	"I was ready to leave"		X	X			X

X's represent additional relevant statements that illustrate each code/theme

Table 3. Characteristics of patients interviewed

Patient Characteristics (n=16)	n (%)
Female sex	8 (50)
Race, white or Caucasian	16 (100)
Medicaid insurance	4 (25)
Diagnosis of cancer	9 (56)
Ostomy	6 (38)
Surgical approach,	
Laparoscopic	9 (56)
Laparoscopic/robotic	3 (19)
Laparoscopic/pfannenstiel,	1 (6)
Robotic	1 (6)
Converted to open	2 (13)
Visiting nurse service	9 (56)
Caregiver at home	16 (100)
Spouse/significant other	11(68)
Child	3 (19)
Parent	2 (13)
Length of stay, mean (range), days	7 (3-22)
Age, mean (range), years	58(29-94)

Table 4. Theme 1: How patients form expectations about what their major abdominal surgery is going to be like

<i>Domain</i>	<i>Exemplar excerpt</i>
<i>Provider</i>	“I thought she was a great doctor. She was you know very informative, the office gave me a lot of information about the procedure, if they had to do it another way, all the different outcomes that would happen, recoveries. Their staff was awesome I had to call a couple of times just with different types of questions about you know the incision or redness and they called me right back; so they have been really really great.” 29-year-old female, no stoma
<i>Other people experience</i>	“You know I asked if I didn’t go for this, how bad would the pain have been? When they said it would have been terrible, then I’d say go for it. Of course I talked to the mother whose daughter had the same type of surgery and well I don’t know the prognosis isn’t that good- she is still suffering, but in my case I figure the few years I have left I’d like to have them without pain. So that’s the main thing, I hope I don’t have too much pain later” 94-year-old female, no stoma
<i>Prior patient experience – appropriate anchor</i>	“I had a C-Section before so I kind of knew what I was in for because it was the same incision as my C-Section. So you kind of are more prepared because you know what the pain is going to be and you kind of know how to sit and that kind of thing.” 29-year-old female, no stoma
<i>Prior patient experience – inappropriate anchor</i>	“I had a hysterectomy back in 2013 and they did it laparoscopically you know and did it vaginally. And somehow my brain thought it was going to be as easy as that one was....But when I think of it logically, yeah you know we are doing internal organ remodeling this is not taking out your uterus and your ovaries and that was it. This is an actual remodel- so yeah that was, that was kind of unexpected. I don’t know why you know somehow in my head I felt okay, this’ll be, I’ve had this before.” 66-year-old female, no stoma
<i>No anchor</i>	“Well I guess I didn’t know what to expect. You know I didn’t, this is a new surgery for me and I really didn’t know what to expect. I mean we talked about it prior to the surgery, but you just don’t know until you actually live it to see what is going to happen” 51-year-old female, no stoma

Table 5. Theme 2: The roles of caregivers and importance of specific caregiver expertise and training for postoperative patient recovery

<i>Domains</i>	<i>Exemplar excerpt</i>
<i>Help with ADL/iADL</i>	“Well a lot. Ummm, you know helping me you know if I needed help you know taking a shower or getting dressed or you know preparing meals, they do a lot.” 51-year-old female, no stoma
<i>Emotional support</i>	“Oh my god, I don't know what I would have done without her. You know I mean she is my support, and I'm hers, but I mean in this particular case she is my support she has helped every way, shape and manner, I'm just saying, so yeah, I am very blessed to have her.” 61-year-old male, no stoma
<i>Special caregiver skills</i>	“She[informal caregiver] was trained on how to give me my lovenox... she wasn't able to make it in time to see my training on the pouch being replaced, but I mean the step, like the step by step information that {nurse practitioner} gave me, anybody could follow it so that is very good.” 67-year-old female, ileostomy
<i>Difficulty obtaining training for caregivers</i>	“My wife the caregiver wasn't trained at all because it sort of happened you know whenever they had time... I should have said: “Hey, now she is here, somebody has got to come and really train her as well.” 74-year-old male, colostomy
<i>Caregiver burden</i>	“ I was starting to get really depressed because my family, it was hard for- it was really hard for them to come up there. My daughter is only 17, she doesn't drive a lot, so we are an hour away and it was really hard for her and she was taking care of my son. So it was a real hardship for her, for my family anyway.” 47-year-old female, ileostomy

(i)ADL – (instrumental) Activity of Daily Living deficiency.

Table 6. Theme 3: Role of patient-provider and healthcare team communication for patient recovery, confidence and perceived quality of care

<i>Domains</i>	<i>Exemplar excerpt</i>
<i>Perception of clinical quality</i>	“Their staff was awesome I had to call a couple of times just with different types of questions about you know the incision or redness and they called me right back; so they have been really really great.” 29-year-old female, no stoma
<i>Confusion</i>	“Then when you get a different nurse coming in, different nurses have different ways of doing things, so I tried to say no we have got to do this, she says no, we’ll do that after, and I go okay you are doing it so go ahead and do it.” 67-year-old female, ileostomy
<i>Setting up appropriate anchors and expectations</i>	“She [the doctor] was you know very informative, the office gave me a lot of information about the procedure, if they had to do it another way, all the different outcomes that would happen, recoveries.” 29-year-old female, no stoma
<i>Communication as a way to build trust and reduce patient anxiety</i>	“Dr. X and I talked about it and he said you know physically he said I think you could go home today but you know what how confident are you today, tell me about your confidence level and I said you know I really do think I need one more day and he said one more day it is. So that you know, I felt a little empowered by that and I knew the day it was I was discharged that I was ready to go.” 66-year-old female, no stoma